

The accompanying editorial, headed “A victory in the battle against hunger”, said the news was “a cause for major congratulation” to the scientists involved, and for the decision to place their findings openly on the internet.

Now here are some readers’ responses: “I will never eat the crap. Are you out of your mind?”, “Sounds like ‘cure for cancer has been found’. Big corps would not allow their markets demise, just like the ‘cancer industry!’”, “GMO is a potential new plague brought about by mankind’s greedy behaviour – birth control and reforms are the solution to overpopulation, not GMO. The EU should ban GMO forthwith”, “The words ‘Play with the natural balance of nature at your peril’ come to mind. It seems akin to taking a buzzsaw to a finely tuned ecosystem. Taking random cuts through the chain of life that binds us all”, “I am NOT for GMO foods because of the KNOWN mutations they cause to the HUMAN genome”, “And there they sit, the Uber-Rich patent holders, their backyards filled with totally resilient wheat, while the rest of the world, without the means to afford it, or even the means to save themselves from starvation, will die in the swamps of Mother Nature’s own selective breeding program.”

Even in the USA, which never experienced the European anti-GM furore, press coverage was followed by angry ripostes. “Scientists have published the first genome of wheat, an achievement that should benefit food security challenged by the Earth’s population, climate change and emerging plant pests,” the *Discovery* channel announced.

“Scientists are too stupid to see the WHOLE picture of what this will do,” said one response, “It will only cause more intolerances, more digestive issues, more toxin accumulation in bowels (because the proteins which were easy to break down are now more ‘resilient’ to everything).” “Kiss wheat as we know it goodbye... Just like Monsanto Corp. There is no more natural soya,” said another. “I love science, but it’s supposed to help us understand nature, not change it.”

Misapprehensions maybe. Atypical perhaps. But the vox pop now available through the Internet on occasions of this sort provides sobering insights for scientists everywhere.

New data issues

The extent to which datasets are openly shared raises privacy fears. **Michael Gross** reports.

In the final years of the last century, the human genome project and Craig Venter’s competing private sequencing effort raised hopes and fears that now, with hindsight, appear naïve. There were hopes for immediate medical benefits from identifying the genetic variations that cause common diseases, and there were fears that the ability to read the human genome would make humans ‘transparent’ in that their traits and indeed their fate could be predicted from the genome, an idea that has been explored in the movie ‘GATTACA’ (1997).

Ten years on, we have come to realise that this promised revolution is more complex, as the human genome has yielded no simple explanations for common medical conditions. In the meantime, however, sequencing capacity, speed and affordability have improved rapidly, such that many ‘personal’ genomes of specific individuals, can now be analysed, and even ancient genomes like that of *Homo neanderthalensis* have become accessible. The multitude of individual genomes, ideally connected to information about the phenotype of the genome carrier, is exactly what

researchers need in order to make medical sense of the genome, after realising that the answers are a lot more complicated than most people thought.

With personal genomics and genome-wide association studies, the hopes and fears of the millennium are returning in a new guise. Initiatives like the 1000 genomes project aim at making genomic information widely available, so it can be analysed by many researchers in different ways. Informed consent of the study participants is deemed sufficient to ward off unwanted side-effects.

On the other hand, not all study participants are sufficiently educated to be able to give their informed consent to a genomic study, and even the most knowledgeable participants cannot look into the future and work out what may happen to their genome data after they enter the public domain.

In the absence of political guidance in a field that moves much faster than legislation, bioethics experts in academia are attempting to set guidelines for good practice. This month, they held the first major international meeting on data sharing at St. Hugh’s College, Oxford. Adopting an innovative open discussion format, the conference addressed questions such as:

- How should data-generators be rewarded for their efforts to the scientific community?



- Can scientists promise anonymity of research participants when whole sequences data and phenotypic data are being used for research purposes?
- Should participants be fed back individual findings?
- Are national research governance systems adequate to cope with global data sharing?
- What innovative IT solutions can be brought into this field to address these challenges and further promote data sharing?

Oxford academic Jane Kaye, who organised the conference and chairs the Centre for Health, Law, and Emerging Technologies (HeLEX), is working towards a 'good practice' guide for the sensitive fields surrounding genomics, biobanks, and data sharing, reconciling the interests of researchers and study participants, without unduly hindering research.

Bioethicists working closely with a research project known as MalariaGEN (Malaria Genomic Epidemiology Network) have already developed procedures for the controlled access to genomic data in studies involving vulnerable participants, where the notion

of informed consent is proving problematic.

As malaria mainly affects sub-Saharan Africa, genomic studies of malaria susceptibility necessarily involve DNA samples from individuals with limited experience or understanding of medical research, who might be unable to comprehend what might happen with their genetic information once it became publicly accessible.

"Because we are aware of the limits of consent in such cases, we have decided not to release data without regulation," explains Jantina de Vries, one of the bioethicists involved in the project. In close consultation between researchers, ethics committees, funding bodies and others, MalariaGEN set up a dedicated review panel to control access to the genomic data generated by the project, the IDAC (Independent Data Access Committee). The six members of IDAC, all experts in relevant disciplines, review all requests for access to MalariaGEN data. An application form for people interested in the data is to be found online, and they will have to justify their request with a description of their research interest, typically about a paragraph or two long.

MalariaGEN's data release policy also includes the option of delaying

access for nine months after the date when the researchers who created the data first had access to it, in order to protect the emerging capacity of African researchers.

Some other researchers and institutions appear to think that this much protection is unnecessary. "This area is currently open to debate," admits de Vries. There are many prominent genomics researchers and research funders who argue that unrestricted open access to genomic data — with consent taken to imply that the DNA donors understand the full implications of their participation — is the best way to promote scientific progress in the pursuit of better understanding of serious diseases. The bioethicists working with MalariaGEN however believe that a managed approach to data-release is a more sustainable and appropriate approach to the promotion of science in a global context.

"We see our approach as a contribution to the debate," says de Vries. "It shows that such research can be done in an ethical way."

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GM salmon loom

A new genetically modified salmon is under consideration in the US. **Nigel Williams** reports.

A genetically modified salmon is under consideration by the US Food and Drugs Administration (FDA) which could sanction the first such modified animal for human consumption. They announced earlier this month an analysis which found the fish safe to eat and unlikely to harm the environment.

Atlantic salmon usually do not grow in the winter and take three years to mature. Aqua Bounty Technologies of Waltham, Massachusetts, has invested more than 14 years and \$60 million developing and seeking approval of its AquAdvantage salmon, which incorporates genetic material from a Chinook salmon and a pout fish. The company says its fish look and taste like non-engineered North Atlantic salmon, consume up to 25 per cent less food and reach market weight in half the time.

If the FDA's Center for Veterinary Medicine approve the fish, Aqua Bounty Technologies believe it could be in commercial production within a year, and available to purchase within two years.

To reduce the risk to the environment, any approval will

require that the fish are raised on farms inland. But critics are concerned. Andrew Good of the Atlantic Salmon Federation says he wants a thorough risk assessment of the GM salmon to be conducted to protect wild salmon.



Speeding up: A new genetically modified version of the Atlantic salmon here is claimed to reach market weight in half the time of conventional fish. (Picture: Photolibrary.)